

The "Sickle Cell Advocate"

Saving sufferers from pain, and
securing a pain free future



Speaking to Prevent the
Unspeakable

Houston I Think We Have A Problem!

Main issue sickle cell sufferers face in crisis situations:

- Trying to convince the medical field how bad they need medical attention

Introducing The SC Advocate

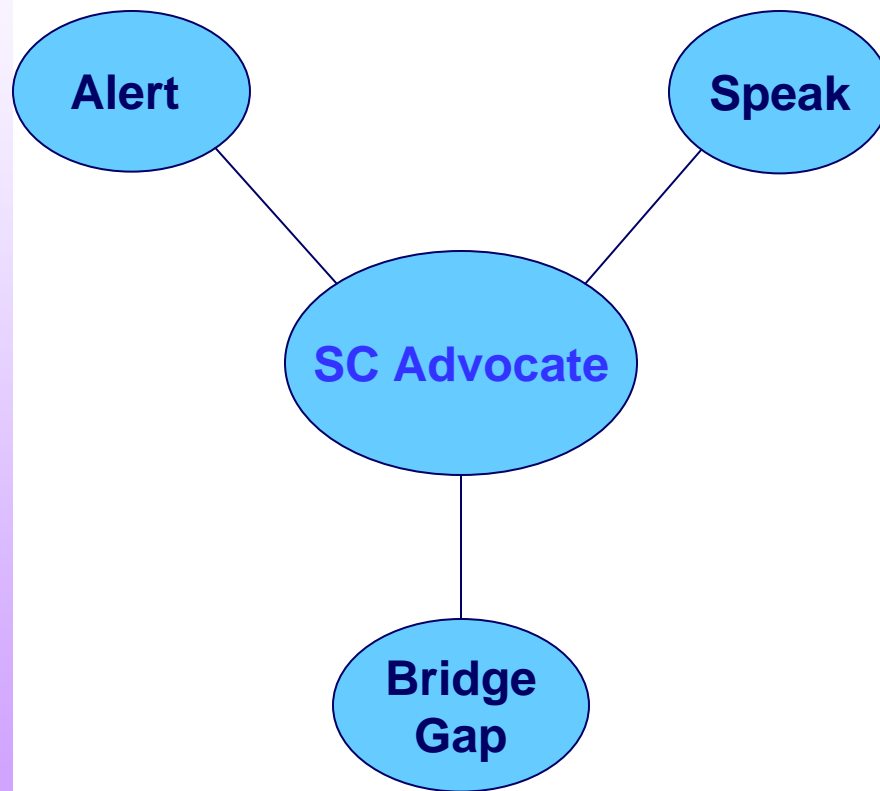
Created By

- Arizona Department of Health Services
Office for Children with Special Health Care Needs
- Adult Sickle Cell Patients
- Parents with children with sickle cell anemia

What is the Sickie Cell Advocate?

- The SC Advocate is a USB Flash Drive device that will contain the sickle cell sufferers medical information. This information will be important in assisting health professionals to provide the best appropriate care for sickle cell patients in an urgent/emergency situation. The SCA will serve as a guide to the patient's sickle cell medical needs. The SCA will be endorsed by local hematologists and primary care physicians confirming that this is a sickle cell disease patient and sees a doctor regularly.

It's objective:



- **Alert:** "This is my patient, he/she has sickle cell disease"
- **Speak:** "The pain medication this patients uses is ???? the dosage is ????"
- **Bridge Gap:** "If you have any questions please feel free to contact me at: Dr. Uno Who (123) 456-7890"

Why do we need the SC Advocate?

This is a key issue in the care of patients with sickle cell disease, all of which require immediate attention therapy with opioids.

Adult patients become tolerized to opioids, and require larger doses of medications.



Why do we need the SC Advocate?

- The rotating nature of the staff in most emergency rooms means that patients with sickle cell pain crises often see different providers with each visit.

The likelihood of an admitting nurse or attending doctor remembering the sickle cell sufferer, or wanting to treat them again is unlikely due to their opioid needs.

Why do we need the SC Advocate?

- Consequently, patients frequently are under medicated, because an ER physician may (reasonably) be cautious with an unfamiliar patient and begin with 2 mg of intravenous hydromorphone (Dilaudid), when the patient might require 8 mg every 45 minutes **for a total of 5 doses to achieve adequate pain management.**
- **The more dosage of pain medication scenario** often evokes a confrontation between patient and staff. The patient demands more medication since the administered amount is inadequate. The staff becomes defensive, and begins to question whether the patient is simply seeking drugs.
- **Hostility develops on both sides.** In this context, which is unpleasant for patient and staff, reasonable medical care is not possible.

Advantage of the SC Advocate



First

- Treatment can begin quickly, often within minutes of the patient's arrival. The nature of emergency room care means that patients with vaso-occlusive crisis pain may wait for long time periods for evaluation and treatment. Almost as a matter of course, the patient's frustration increases with the rising pain levels during this time. The interaction of an often-harried ER physician and a patient with sickle cell disease that has waited for hours to be seen frequently is not congenial.

Advantage cont.....

Second

- The staff becomes familiar with the doctors signature, the use of the ID and the returning patient and their analgesic requirements for pain control

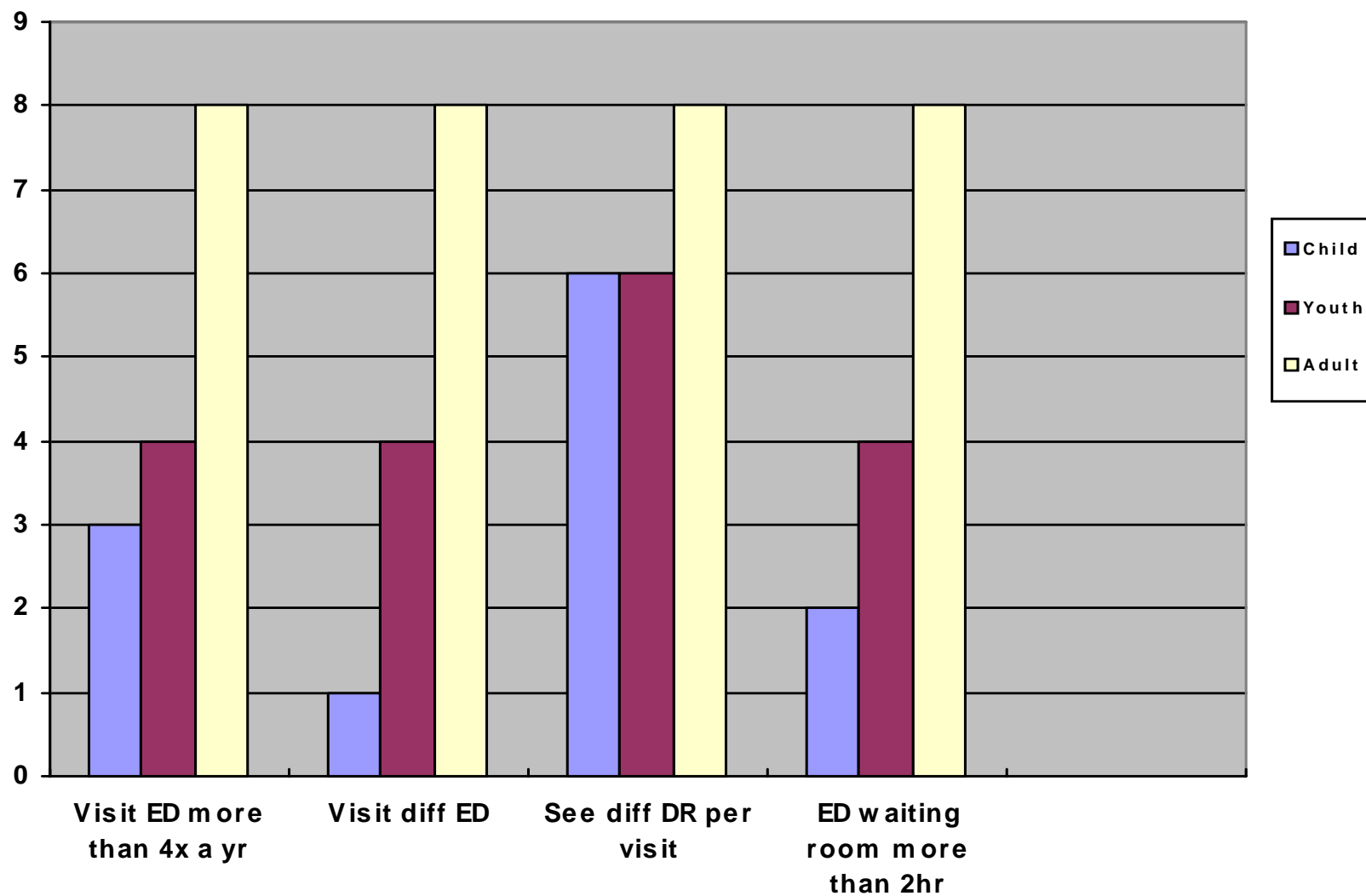
Who Benefits From the SC Advocate

- A recent study with children, youths, and adults, showed that all had ED issues which could have been eliminated by having the SC Advocate.



Studies show that 1 out of 10 Children youths & Adults

Have ED issues which can be
eliminated by having the SC Advocate



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What are the Devastating effects of Sickle Cell Disease?

- Chronic Unbearable Pain
- Blindness
- Stroke
- Heart Disease
- Leg Ulcers
- Depression
- Hip Replacements
- Loss of Limbs
- Eventually Death

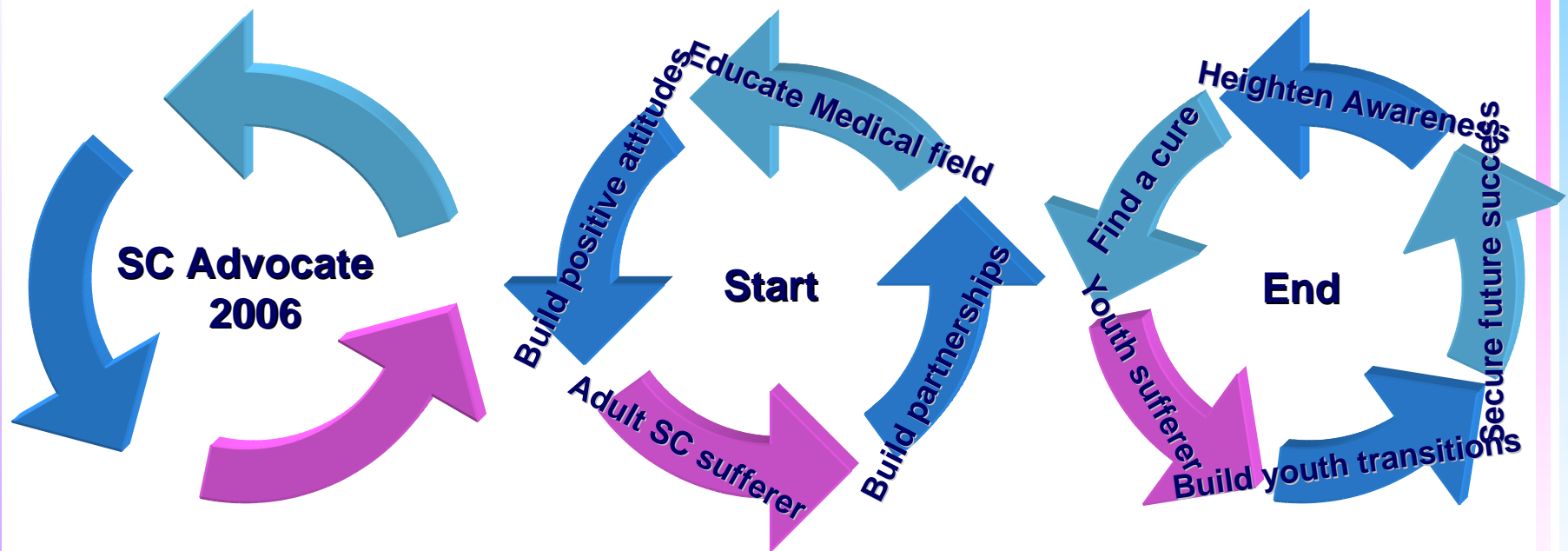
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The SC Advocate Helps Sufferers Move from Being

- Silent Victims to
- Gaining confidence in the medical field to
- receiving proper medical treatment to
- Producers of community and individual well-being



Joining Our Strengths and Yours, Building a community partnership for pain free success.



Key Benefits

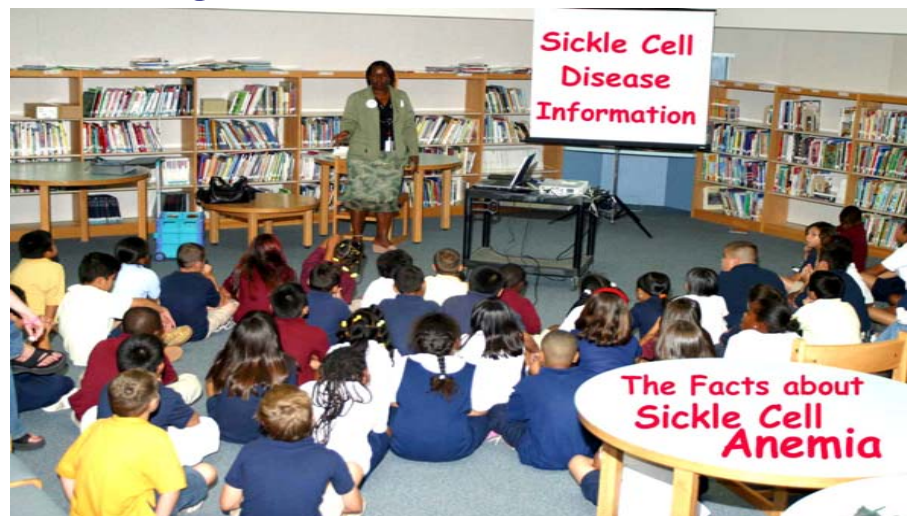
- Despite advances in treatment, sickle cell is in danger of becoming a "forgotten disease," with government funding for research and public information declining to a trickle compared to a few years ago. Quest to Cure and Dept. of Health Services program examines the devastating impact of sickle cell disease on these transitional youths, adults and their families and caregivers. The SC Advocate will be an important tool for increasing awareness in the emergency department and among healthcare and social service providers in community clinics, hospitals, and other settings.

How could partnering with us help?

- 1. Effective in action**
- 2. Ability to open doors**
- 3. Reach larger numbers**
- 4. Economic strength**
- 5. Big brother backing affect**

Parent Led Action Team

- Sponsored by AZ. Dept. of Health Services, Office for Children with Special Health Care Needs
- Benefiting The Sickel Cell Community
- Promoting a Pain Free Future
- Educating to Heighten Awareness



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